



Lesson: The Art of Caregiving

OVERVIEW

In this lesson, students delve into the role of family members acting as caregivers for those who are ill, elderly, disabled or otherwise not able to care for themselves regularly and efficiently. Students examine what family caregivers do, what their unique qualities are and how they cope with the challenges caregiving presents. Students determine the type of support system caregiving family members need in order to take care of others and themselves.

The video clips provided with this lesson are from **The Genius of Marian**, a rich and emotionally complex story about one family's struggle to come to terms with Alzheimer's disease. After Pam White is diagnosed at age 61 with early-onset Alzheimer's, life begins to change, slowly but irrevocably, for Pam and everyone around her. Her husband grapples with his role as it evolves from primary partner to primary caregiver. Pam's adult children find ways to show their love and support while mourning the gradual loss of their mother. Her eldest son, Banker, records their conversations, allowing Pam to share memories of childhood and of her mother, the renowned painter Marian Williams Steele, who had Alzheimer's herself and died in 2001.

For additional information and educational resources on Alzheimer's disease and the caregiving involved, visit the PBS site for the documentary ***The Forgetting: A Portrait of Alzheimer's*** (<http://www.pbs.org/theforgetting/watch/index.html>).

POV offers a lending library of DVDs that you can borrow anytime during the school year—FOR FREE! Get started by joining our [Community Network](#).

OBJECTIVES

By the end of this lesson, students will:

- Describe Alzheimer's and its impact on those diagnosed, as well as their friends and family
- Illustrate the role of family members in caregiving
- Determine what caregiving involves
- Assess the impact of illness and related circumstances and caregiving on a family
- Propose ways to support family members who are caregivers

GRADE LEVELS

9-12

SUBJECT AREAS

Language Arts, Social Studies, Health

MATERIALS

- Internet access and equipment to show the class online video
- Chart paper and markers
- Any printouts of resource materials downloaded from provided URLs (teacher choice regarding what to print and distribute)

ESTIMATED TIME NEEDED

One 50-minute class period

FILM CLIPS

Clip 1: Introducing Pam White (Length: 2:17 min.)

This clip begins at 2:33 with Banker saying, “Mom, where are you?” and moving through a house with a camera. It ends at 4:50 with the title “**The Genius of Marian**” on the screen.

Clip 2: And I Don’t (Length: 2:21 min.)

This clip begins at 8:46, with a caption introducing Banker, Pam’s son, and an image of Banker and Pam looking through paintings while Banker says, “So, what do you want to talk about today?” It ends at 11:07 with Pam in a car saying, “Careful.”

Clip 3: Never Happened Before (Length: 3:27 min.)

This clip begins at 16:57, with an image of Pam, a baby and Pam’s son Luke in the kitchen and Luke saying, “I remember right about the time she was diagnosed...” It ends at 20:24 with Luke saying, “And that had never happened before.”

Clip 4: Medication (Length: 3:31 min.)

This clip begins at 20:37, with a view of a bedroom with an unmade bed and with Luke saying, “Hi, Mom.” It ends at 24:08 with Pam saying, “But I don’t want to take that.”

Clip 5: I Think About It All The Time (Length: 1:05 min.)

This clip begins at 23:09 with an image of photos and with Pam’s son saying, “Unfortunately, you do have Alzheimer’s.” It ends at 24:14 with an image of a baby and Ed White in the background saying, “Hey, you.”

Clip 6: That’s Not Going to Happen (Length: 2:45 min.)

This clip begins at 27:24 with Ed White in the kitchen saying, “So, we met.” It ends at

30:09 with Ed White, in his home office, saying, “That’s not going to happen.”

Clip 7: I’m Really Worried About Him (Length: 2:39)

The clip begins at 54:37, with an image of a boat on the water and Ed White saying, “We’ve had less than perfect days before.” It ends at 57:16 with an image of a setting sun viewed from the window and Pam’s daughter saying, “And I think the result is not good.”

ACTIVITY

1. Divide students into small groups. Distribute a sheet of chart paper and a marker to each group. Have one student per group divide the sheet into four columns and mark the columns across the top from left to right: **SITUATION**; **SUPPORT**; **FAMILY MEMBER**; and **IMPACT**.
2. Tell the students to share stories within their groups about times when people in their families were in need of more support than usual. Explain that they can talk about any type of situation, from illness to school issues to employment troubles to difficult decisions. **NOTE:** Students should *volunteer* for this exercise. Instruct each student telling a story to share how support was offered to the family member in question; who provided that support; and how the situation played out among family members. Ask one member per group to jot down notes in each column and to include particular examples for each category.
3. Invite groups to share what they discovered through their conversations. After each group presents, have the class discuss similarities across the categories, with particular emphasis on impact. Have the class focus on the impact of stressful situations on family members: How do family members respond? How do they feel? How do they interact with the person in need? How do they cope?
4. Affirm that family members hold a lot of responsibility when it comes to taking care of someone in the family who has a particular need. Explore with students as a class what can occur within a family when circumstances become difficult or stressful. Tell the students they will explore an example of how one family coped during a challenging situation as they watch some clips from a film about a person with a disease called Alzheimer’s.
5. Ask students if they know what Alzheimer’s is and to describe it. Use the Intro to Alzheimer’s info sheet to give students some background on the disease.
6. Tell students they will see how Alzheimer’s affects a person. Describe the film *The Genius of Marian*. Show:
 - **Clip 1: Introducing Pam White** (Length: 2:17 min.)
 - **Clip 2: And I Don’t** (Length: 2:21 min.)
 - **Clip 3: Never Happened Before** (Length: 3:27 min.)
 - **Clip 4: I Don’t Want to Take That** (Length: 3:31 min.)

After students view the clips, ask them to share what seems to happen to a person with Alzheimer's and how a person might feel knowing he or she is slowly losing the ability to function normally.

7. Invite students to write about (in the form of a journal entry or personal essay) and share observations or experiences that frame for them the role family members play in caring for those who have special needs or require a more intensive level of support. Ask them to consider the role family members have as caregivers when a close family member has Alzheimer's. What are the challenges? What are the expectations? What are the reactions?
8. Validate student responses. Show:
 - **Clip 5: I Think About It All The Time** (Length: 1:05 min.)
 - **Clip 6: That's Not Going to Happen** (Length: 2:45 min.)
 - **Clip 7: It Seems Impossible** (Length: 2:39 min.)
9. After viewing, divide students into small groups. Assign each group one of the following categories:
 - Pam White's family caregivers
 - Role of the caregivers
 - How the family interacts with Pam
 - How Pam feels
 - How the family feels
 - How the family copes

Have each group discuss its category and then present the group's thoughts to the class.

10. Have students reflect on and then discuss the challenges of caregiving, especially when family is charged with the task. Again, students can draw on personal experiences or observations. Probe with students the benefits and downsides of family as caregivers.
11. Ask students to reflect on how Pam's family members cope with the challenge of caregiving. Broaden the conversation to probe whether what this family does might be similar to what other families do to manage the stress of crisis, illness, trouble and other similar events.
12. Have students reflect on the situations they discussed in the early part of the lesson, the challenges of Alzheimer's and Pam White's family. Based on these circumstances, what tips might they give to caregivers that will help them care for themselves as they tend to family members in need? Ask students to offer suggestions. Record and group the suggestions according to the themes that emerge (these might include communication, honesty and being informed about

the illness/situation.) If you would like to use a prompt, a good choice would be this article, which lays out categories for self-care for caregivers: “Taking Care of YOU: Self-Care for Family Caregivers” <https://www.caregiver.org/taking-care-you-self-care-family-caregivers>.

HOMEWORK: Instruct students to log onto the Genius of Caring page on the **Genius of Marian** website <http://www.GeniusofCaring.com> and find the **Story Sharing Project**. This project captures the complex emotional experience of caring for loved ones and offers visitors a place to share stories and connect with others. Each student should read some of the stories and then write a personal story, about a family member with Alzheimer’s or another issue that requires family caregiving. They will share their stories during the next class and then have the option of posting them on the website. (While the site’s focus is on Alzheimer’s, the issue of caregiving is universal, and thus a story could be relevant regardless of the topic.)

EXTENSIONS

From the Front Lines

In the film, students observe how Pam negotiates and responds to the impact of Alzheimer’s on her mind and body. **Show Clips 1-4**. Have students further explore how people negotiate debilitating circumstances that complicate their lives in a significant way. Use all or some of the following discussion prompts:

- How do people respond to these challenges?
- How do they handle what could happen to them over the long term?
- What support systems do they need?
- What support services do they need (i.e., external caregivers)? What are the pros and cons of these support services, particularly from the perspective of the caregiving family and the person living with Alzheimer’s?

To address these questions, students may find it helpful to read some stories. Possible sources include:

- **Alzheimer’s Association: Personal Stories**
http://www.alz.org/living_with_alzheimers_8510.asp
- **The Guardian: “Living with Death” by Shahesta Shaitly**
<http://www.theguardian.com/lifeandstyle/2011/jun/19/living-death-terminal-illness-cancer>

The Economics of End-of-Life

Pam White’s resources allow her to remain at home, receive quality health care and later, as the illness progresses, have a personal health aide. But not everyone who has Alzheimer’s or another terminal illness has the economic capacity for this type of care and treatment. Socio-economic status, unfortunately, plays a role in how terminally ill people live and die. Students can read the article “Alzheimer’s, Poverty Split Elderly Chinese Couple” (<http://newamericamedia.org/2014/03/alzheimers-poverty-split-elderly->

[chinese-couple.php](#)), which introduces a couple dealing with Alzheimer's differently than Pam White and her husband, largely because of economics. Invite students to compare and contrast the two stories and then discuss how all people, regardless of their income levels, can receive equitable health and related long-term care when they are terminally ill.

From History to Risk to Diagnosis: Exploring Alzheimer's Disease

Students delve into various aspects of Alzheimer's to understand everything from its formation in the brain to its impact. Students can be divided into small groups to research and present on one aspect of the disease, using the documentary *The Forgetting: A Portrait of Alzheimer's* and its website, particularly the page with materials for educators, <http://www.pbs.org/theforgetting/educators/index.html>. As a class, students can explore medical and scientific activity to date centered on researching and fighting the disease.

RESOURCES

Administration on Aging: National Family Caregiver Support Program

http://www.aoa.gov/aoa_programs/hcltc/caregiver/index.aspx

Alzheimer's Association: Kids & Teens

http://www.alz.org/living_with_alzheimers_just_for_kids_and_teens.asp

Alzheimer's Society: Explaining Dementia to Children and Young People

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=108

Caregiver Action Network

<http://caregiveraction.org/>

Family Caregiver Alliance

<https://www.caregiver.org/>

KidsHealth: Alzheimer Disease

<http://kidshealth.org/kid/grownup/conditions/alzheimers.html>

National Alliance for Caregiving

<http://www.caregiving.org/>

***The New York Times*: "Caring for the Alzheimer's Caregiver"**

http://well.blogs.nytimes.com/2014/02/17/caring-for-the-alzheimers-caregiver/?_php=true&_type=blogs&_r=0

A Quick Look At Alzheimer's: Five "Pocket" Films to Increase Understanding of a 21st Century Epidemic

<http://aboutalz.org>

STANDARDS

Common Core State Standards for English Language Arts & Literacy in History/Social Studies, Science, and Technical Subjects

(http://www.corestandards.org/assets/CCSSI_ELA%20Standards.pdf)

[SL.9-10.1](#) Initiate and participate effectively in a range of collaborative discussions (one-on-one, in groups and teacher-led) with diverse partners on grades 9-10 topics, texts and issues, building on others' ideas and expressing their own clearly and persuasively.

[SL.11-12.1](#) Initiate and participate effectively in a range of collaborative discussions (one-on-one, in groups and teacher-led) with diverse partners on grades 11–12 topics, texts and issues, building on others' ideas and expressing their own clearly and persuasively.

[SL.9-10.2](#) Integrate multiple sources of information presented in diverse media or formats (e.g., visually, quantitatively, orally) evaluating the credibility and accuracy of each source.

[SL.11-12.2](#) Integrate multiple sources of information presented in diverse formats and media (e.g., visually, quantitatively, orally) in order to make informed decisions and solve problems, evaluating the credibility and accuracy of each source and noting any discrepancies among the data.

[W.9-10.3](#) Write narratives to develop real or imagined experiences or events using effective technique, well-chosen details and well-structured event sequences.

[W.11-12.3](#) Write narratives to develop real or imagined experiences or events using effective technique, well-chosen details and well-structured event sequences.

[RI.9-10.7](#) Analyze various accounts of a subject told in different mediums (e.g., a person's life story in both print and multimedia), determining which details are emphasized in each account.

[RI.11-12.3](#) Analyze a complex set of ideas or sequence of events and explain how specific individuals, ideas or events interact and develop over the course of the text.

[RI.11-12.7](#) Integrate and evaluate multiple sources of information presented in different media or formats (e.g., visually, quantitatively) as well as in words in order to address a question or solve a problem.

Content Knowledge: (<http://www.mcrel.org/standards-benchmarks/>) a compilation of content standards and benchmarks for K-12 curriculum by McRel (Mid-continent Research for Education and Learning).

Behavioral Studies, Standard 4: Understands conflict, cooperation and interdependence among individuals, groups and institutions

Health, Standard 3: Understands the relationship of family health to individual health

Health, Standard 4: Knows how to maintain mental and emotional health

Family/Consumer Sciences: Family Life, Standard 1: Understand the family as the basic unit of society

Family/Consumer Sciences: Family Life, Standard 2: Understand the impact of the family on the well-being of individuals and society

ABOUT THE AUTHOR

Michele Israel owns Educational Writing & Consulting (www.micheleisrael.com), where she works with large and small educational, nonprofit and media organizations to bolster products and programs. Her rich career spans more than 25 years of successful experience developing educational materials and resources, designing and facilitating training, generating communication materials and grant proposals and assisting in organizational and program development. Her long list of clients includes the Public Broadcasting Service, the Association for Supervision and Curriculum Development, Teaching Tolerance, Aspiranet, the New York City Department of Health and Mental Hygiene, WETA Public Television, *Religion & Ethics NewsWeekly* and the New York City Harm Reduction Coalition,

Intro to Alzheimer's

The following information has been reprinted with permission from the Alzheimer's Association. Visit www.alz.org for more information.

Alzheimer's and Dementia Basics

Alzheimer's is the most common form of dementia, a general term for memory loss and other cognitive abilities serious enough to interfere with daily life. Alzheimer's disease accounts for 60 to 80 percent of dementia cases.

Alzheimer's is not a normal part of aging, although the greatest known risk factor is increasing age, and the majority of people with Alzheimer's are 65 and older. But Alzheimer's is not just a disease of old age. Up to 5 percent of people with the disease (more than 200,000 people in the United States alone) have early-onset Alzheimer's (also known as younger-onset Alzheimer's), when symptoms appear before age 65.

Alzheimer's worsens over time. Alzheimer's is a progressive disease, in which dementia symptoms gradually worsen over a number of years. In the early stages of Alzheimer's, memory loss is mild, but with late-stage Alzheimer's, individuals lose the ability to carry on conversations and respond to their environments. Alzheimer's is the sixth leading cause of death in the United States. Those with Alzheimer's live an average of eight years after their symptoms become noticeable to others, but survival can range from four to 20 years, depending on age and other health conditions.

Alzheimer's has no current cure, but treatments for symptoms are available and research continues. Although current Alzheimer's treatments cannot stop Alzheimer's from progressing, they can temporarily slow the worsening of dementia symptoms and improve quality of life for those with Alzheimer's and their caregivers. Today, there is a worldwide effort under way to find better ways to treat the disease, delay its onset and prevent it from developing.

Symptoms of Alzheimer's

The most common early symptom of Alzheimer's is difficulty remembering newly learned information. Our brains change as we age, just like the rest of our bodies. Most of us eventually notice some slowed thinking and occasional problems with remembering certain things. However, serious memory loss, confusion and other major changes in the way our minds work may be a sign that brain cells are failing.

The most common early symptom of Alzheimer's is difficulty remembering newly learned information, because Alzheimer's changes typically begin in the part of the brain that affects learning. As Alzheimer's advances through the brain, it leads to increasingly severe symptoms, including disorientation, mood and behavior changes; deepening confusion about events, time and place; unfounded suspicions about family, friends and

professional caregivers; more serious memory loss and behavior changes; and difficulty speaking, swallowing and walking.

Alzheimer's and the Brain

Microscopic changes in the brain begin long before the first signs of memory loss. The brain has 100 billion nerve cells (neurons). Each nerve cell connects with many others to form communication networks. Groups of nerve cells have special jobs. Some are involved in thinking, learning and remembering. Others help us see, hear and smell.

To do their work, brain cells operate like tiny factories. They receive supplies, generate energy, construct equipment and get rid of waste. Cells also process and store information and communicate with other cells. Keeping everything running requires coordination, as well as large amounts of fuel and oxygen.

Scientists believe Alzheimer's disease prevents parts of a cell's factory from running well. They are not sure where the trouble starts. But, as in a real factory, backups and breakdowns in one system cause problems in other areas. As damage spreads, cells lose their ability to do their jobs and eventually die, causing irreversible changes in the brain.

Alzheimer's Biomedical Research Today

Researchers are working to uncover as many aspects of Alzheimer's disease and related dementias as possible. Ninety percent of what we know about Alzheimer's has been discovered in the last 15 years. Some of the most remarkable progress has shed light on how Alzheimer's affects the brain. The hope is that this better understanding will lead to new treatments. Many potential approaches are currently under investigation worldwide.

For more information, visit www.alz.org/alzheimers_disease_what_is_alzheimers.asp